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Long-term quality of life of caregivers of cardiac arrest survivors and the impact of witnessing a cardiac event of a close relative

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A B S T R A C T

Background: The incidence of cardiac arrest is high, with a poor survival rate of 8–14%. Currently, only limited evidence is available about long-term consequences of cardiac arrest on quality of life of caregivers.
Aims: First, to determine the level of daily functioning and quality of life in caregivers of cardiac arrest survivors two years after the cardiac arrest. Second, to study the long-term impact of witnessing the event of a cardiac arrest.
Methods: A longitudinal cohort study including caregivers of cardiac arrest survivors. Participants received a questionnaire at home. Outcome variables were instrumental daily activities(FAI), emotional functioning (HADS), fatigue(FSS), caregiver strain(CSI), impact of event(IES), and quality of life(SF36).
Results: 57 caregivers (89% female, age 56,9 ± 12 years) participated. Two years after the cardiac arrest, quality of life of caregivers equals that of the general population, although almost 30% still scored high on the Impact of Events Scale. Mean IES-, FSS-, CSI and FAI-scores were increased as compared to the general population ($P < 0.001$). Two years after the cardiac arrest, caregivers that witnessed the resuscitation (IES = 23.6 ± 14.9) still experienced significantly more trauma related stress than caregivers that did not witness the resuscitation (11.9 ± 12.5; $p < 0.01$).
Conclusions: Two years after the cardiac arrest, quality of life of caregivers is quite good, but almost one third of the caregivers still experience a high level of trauma-related stress, especially in those that witnessed the resuscitation. Future research will have to focus on the effectiveness of support programs for caregivers of survivors of cardiac arrest.

Introduction

The incidence of cardiac arrest in the Netherlands is estimated 60–92 per 100.000 persons per year [1,2]. Just a small minority (8–14%) survives and can be discharged from the hospital [2,3]. At the time of discharge from the hospital, 47–50% of the survivors rated their level of functioning moderate to severe [2,3]. These limitations in daily functioning and quality of life after cardiac arrest may be due to cardiac and neurological residual symptoms. Sixteen to fifty percent of the survivors had neurocognitive deficits [4,5] such as memory problems, attention problems and difficulties in executive functioning [7] due to post-hypoxic encephalopathy [6] which can impact physical and psychosocial functioning [8]. The level of functioning after a cardiac arrest improves over time. Although six months after cardiac arrest, 23% percent of the survivors still needed help in daily functioning [9], returned 96% to their pre-arrest level of daily functioning one year after the arrest [10].

Given the impact on functioning of the patient, caregivers may also experience consequences of the cardiac arrest, such as reported in caregivers of patients with brain injury [11]. One year post cardiac

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arrest, both patients and caregivers reported an improve in wellbeing [12]. However, after one year, 40% of the caregivers still experienced a high impact of the event. Partners of survivors of cardiac arrest can experience long-term symptoms such as mood disturbances, posttraumatic stress and strain as well [13]. Partners often experience even more stress and feelings of anxiety than patients themselves. A variety of 15–64% of the partners showed a higher level of strain [12–14]. Even 25 months after the cardiac arrest, relatives were still coping with major changes in their living conditions [9]. Sixty percent experienced psychosomatic problems, such as lack of interest, sleep disturbances, restlessness, decreased libido, reduction of impulse, weight loss and loss of appetite. Fifty percent reported lack of social support [9]. A systematic review on psychological distress in partners of patients with implantable cardioverter defibrillator (ICD) showed that the level of psychological distress was at least as high among partners of patients, as it was among the patients themselves [15]. Furthermore, most of the included studies suggested a decrease in the experienced amount of stress during the first year post-implantation. The ICD-implantation indication, comorbidity, and the partner's age and psychological status were related to the level of distress and quality of life [15].

However, despite all information retrieved during the past years, only restricted information is available about the long-term consequences of cardiac arrest on the caregivers. The aim of this study was therefore to determine the impact of a cardiac arrest on long-term daily functioning and quality of life in caregivers of survivors two years after their cardiac arrest. The second aim was to study a potential relationship between the attendance and possible participation of the caregivers during cardiopulmonary resuscitation (CPR) and long-term functioning.

Methods

Study population

For the current study, caregivers of patients who participated in the ALASCA study (Activity and Life After Survival of a Cardiac Arrest) were approached 2 years after cardiac arrest to fill in a questionnaire. (ALASCA) [16]. Inclusion of participants in the original ALASCA study lasted from April 2007 till November 2010. Only those patients included before March 2009 were invited to participate in this two year follow-up. Two years post cardiac arrest, caregivers received a self-report questionnaire by post together with an informed consent form and a return envelope at their home. They were invited to fill in the questionnaire and to return it with the informed consent form.

For the original ALASCA study all patients, admitted with a cardiac arrest to one of the seven participating hospitals in the south of the Netherlands, that were still alive two weeks after admission, were asked to participate. In addition, caregivers of patients were invited to participate. Caregivers are defined as partner, spouse or significant other that is most closely related to the patient. Detailed in- and exclusion criteria for patients after their cardiac arrest are presented elsewhere [16]. All participants retrieved questionnaires 2 weeks, 3 months and 1 year after the cardiac arrest, as part of a larger study [16].

Data collection

Ethical considerations

The Medical Ethics Committee of the University Hospital Maastricht/Maastricht University approved the ALASCA study. The study is registered in a public trial registry [ISRCTN74835019]. The original follow up period in the ALASCA trial was 1 year.

For the current project, The Medical Ethics Committee of the Maastricht University Medical Centre approved an addendum to the original ALASCA study. All caregivers that were contacted were sent questionnaires that had to be self-completed at home by post and thy were asked for informed consent.

The following assessment instruments were used:

Quality of Life

- The **Medical Outcomes Study 36-item Short Form Health Survey (SF-36; version 1)** which is a multi-dimensional instrument for the measurement of quality of life and consists of 36 items that encompass 8 different dimensions [17]. A physical component scale (PCS) and mental component scale (MCS) can be calculated [18]. For each subscale, scores are transformed to a scale from 0 (worst health) to 100 (best health).
  The **EuroQol 5D (EQ-5D)**. The EQ-5D is an instrument for quality of life and consists of 5 items, each encompassing one dimension (mobility, self-care, usual activities, pain/discomfort anxiety/depression). Each item can be scored on a three-point scale from 1 (no problems) to 3 (extreme problems) [6]. The total score can be converted into a health state. In addition, participants are asked to rate their current health state on a visual analogue scale (VAS), ranging from 0 to 100 [9].

Emotional Functioning

- The **Hospital Anxiety and Depression Scale (HADS)** is a short questionnaire, containing 14 items that identify the presence of mood disturbances in non-psychiatric hospital outpatients. The HADS has a depression subscale (7 items), and an anxiety subscale (7 items) [20,21]. Items are scored on a four-point scale, ranging from 0 to 3.
- The **Impact of Event Scale (IES)** is a 15-item questionnaire to assess characteristic responses to traumatic stressors on two dimensions: intrusion and avoidance [22–24]. The total score varies between 0 and 75 and provides a total subjective stress-score. A higher score indicates a higher impact of events

Fatigue

- **The Fatigue Severity Scale (FSS)** is a 9 item self-report instrument that assesses the impact of severe fatigue on daily functioning. Items can be scored from 1 (complete disagreement) to 7 (complete agreement) [25]. The total score is a mean score. A higher score indicates a higher impact of fatigue on daily functioning

Caregiver strain

- The **Caregiver Strain Index (CSI)** measures the amount of strain in relation to care giving, experienced by a patient's partner or significant other [26,27]. It is composed of 13 yes/no statements. A higher score indicates a higher level of strain and a positive response to seven or more items indicates a situation of overload,

Instrumental daily activities

- The **Frenchay Activity Index (FAI)** is a questionnaire with 15 items that measures the patient's ability to perform more complex activities. Items are scored on a four-point scale, ranging from 0 to 3 points. Total scores range between 0 (low ability) and 45 (high ability) [28].

More detailed information on the selection and the background of the outcome variables is presented in the design article of the original ALASCA study [16].

Statistical analysis

Demographical characteristics and mean scores are presented using descriptive statistics. The number and percentage of participants with a score above or below the cut-off value are reported. The cut-off values

of the FSS [25], CSI [26], IES [29] and HADS [30] were used as presented in the literature. If not available, a cut-off score was calculated using the mean score in the Dutch population ± one standard deviation [17,19,28]. The procedure concerning missing values was set a priori: In case of ≥15% missing values within a single questionnaire, the total score was scored as missing. In cases with < 15% missing, the total score was imputed based on the mean score on the available values.

Total scores of participants on functioning and quality of life were compared with scores on these variables available in the literature of the general Dutch population1 [7,19,20,22,23,28,32,33]. To examine the difference between scores of the study population and scores of this control population, the one-sample T-test was used. In order to compare functioning of partners one and two years after the cardiac arrest a paired samples T-test (normal distribution) or the Wilcoxon Signed Rank test (a nonparametric distribution) was used. To test whether functioning of partners witnessing CPR or those who actually performed CPR themselves differed we used an Independent samples T-test (normal distribution) or Mann Whitney *U* test (a nonparametric distribution). A *p*-value of ≤0.05 was considered statistically significant. Statistical analysis was performed using the software package SPSS version 18.0.

Results

As shown in Fig. 1, a total number of 153 caregivers of patients, who survived a cardiac arrest between April 2007 and March 2009, gave consent at the start of the ALASCA study. One year after the cardiac arrest, 131 caregivers still participated in the study and received a questionnaire of whom 84% completed it. As shown in Fig. 1, Two years after the cardiac arrest 107 caregivers still participated in the study and were sent a questionnaire. Of the 107 questionnaires sent, 57 (53%) were returned and filled out correctly. The other 50 caregivers did not complete or return the questionnaire, due to a variety of reasons, as listed in Fig. 1.

Main demographics of the responders are presented in Table 1. Fifty-four caregivers were the patient's partner or spouse, one caregiver is another relative. Of two patients, the relationship was labeled as caregiver by the patient (as registered at the start of the study in the patient's questionnaire), but the exact relationship was unknown. At the moment of the cardiac arrest, the cardiac arrest survivors had a mean age of 60 years and 80% of them were male. Only 1% of the patients had a cardiac arrest before, but 60% had a cardiovascular history. In 4% of the cases the patient was discharged to a nursing home, the other 96% of the patients were directly discharged home.

Of the responders 89.5% was female, whereas 96% of the non-responders was female. No statistically significant gender- (Fisher's Exact Test p = .28) or age-related (t = −0.038, p = .97) differences between responders and non-responders were detected. No change in working situation of the caregivers occurred between one and two years after the cardiac arrest. Thirty-four caregivers were employed before the cardiac arrest and 25 (74%) of them still worked equal hours, 7 people decreased working hours and one person stopped. This situation equals that of one year after the cardiac arrest.

Level of functioning two years after a cardiac arrest

Quality of life two years after a cardiac arrest wasn't perceived different for partners of patients that survived a cardiac arrest as compared to the general population (as shown in Table 2). In addition, FAI-scores representing activities in daily living for partners in the study group (33 ± 0.1 5.8) were significantly higher as compared to the general population (25.9 ± 9.4); t = 9.431, p < 0.0001) [28]. Caregivers two years after a cardiac arrest reported to be more fatigued (FSS) as compared to the general population [25] (t = 4.24, p = < 0.001). Severe fatigue was present in 21.1% of the caregivers, using the presented FSS cut-off score based on a study among 1482 healthy adults (age 19–81; mean 3.7; SD 1.2) [31].

Twenty-nine percent of the caregivers scored above the cut off score on the Impact of Event Scale two years after the cardiac arrest [22] IES scores differed significantly between the caregivers participating in this study (17.8 ± 14.8)) and general population (8.1 ± 12.3;t = 4.88, p < 0.001). After two years, emotional functioning represented by HADS-scores did not differ significantly from those in the general population for both subscores anxiety (p = .18) and depression (p = .10) [20].

Functioning one and two years after cardiac arrest

To represent changes over time, Table 3 presents scores of the study population one versus two years after the cardiac arrest. Both the current health state (Euroqol-VAS-score (p = .01) and the impact of event (IES-score (p = .03)) decreased significantly between one and two years after the cardiac arrest.

Effect of witnessing and performing CPR

In Table 4 scores of the CPR bystanders and non-bystanders two years after a cardiac arrest are presented. A statistically significant difference in IES-scores between caregivers that witnessed the cardiac arrest (23.6 ± 14.9) and resuscitation and those that did not witness this event is shown (11.9 ± 12.5; t = 3.21, p = .002). But for those that witnessed the resuscitation, no difference in IES-scores was found for caregivers who performed CPR themselves and those who witnessed but did not perform CPR (p = .84).

Discussion

The aim of this study was to examine the long-term (two years) level of daily functioning and quality of life in caregivers of cardiac arrest survivors. Two years after the cardiac arrest, caregivers of cardiac arrest survivors perceive their quality of life as the general population. However, almost one third of the caregivers of cardiac survivors still experienced a higher level of trauma related stress. Caregivers who witnessed the resuscitation experienced more stress than those that did not witness the resuscitation.

This study population has more female (89.5%) than male (10.5%) participants. This percentage reflects the three times higher incidence of cardiac arrest among men [33]. The working situation of caregivers did not change between one and two years after the cardiac arrest: 75% of the caregivers worked equal hours compared to the situation before the cardiac arrest. Previous studies among caregivers of stroke survivors showed percentages of 86–100% [34,35].

The caregivers in our study population do not report a lower quality of life as compared to the general population. Even although the perceived health situation as measured with the Euroqol-VAS decreased between one and two years after the cardiac arrest (p = .01). This finding is consistent with previous studies that found a decrease in health state with an increasing age for the general population [38]. Although the number of caregivers with trauma related stress decreased between one and two years after the cardiac arrest, caregivers still scored high on the Impact of Event Scale two years after the cardiac arrest. Based on cut-off values used, 28.6% of the caregivers still experienced trauma related stress. In fact, the level of stress reactions found in our study group seems even comparable with scores found in persons with a history of major trauma (mental violence/abuse, witness of violence/disaster, work related trauma) [22,23]. Previous research confirmed this finding [36]. Feelings of anxiety are less common two years after the cardiac arrest compared to one year after the event (19.3% versus 26%) [13]. In addition, severe fatigue was present in 21.1% of the caregivers. So far, little research had been conducted regarding fatigue in caregivers. Schneider at al. examined the level of

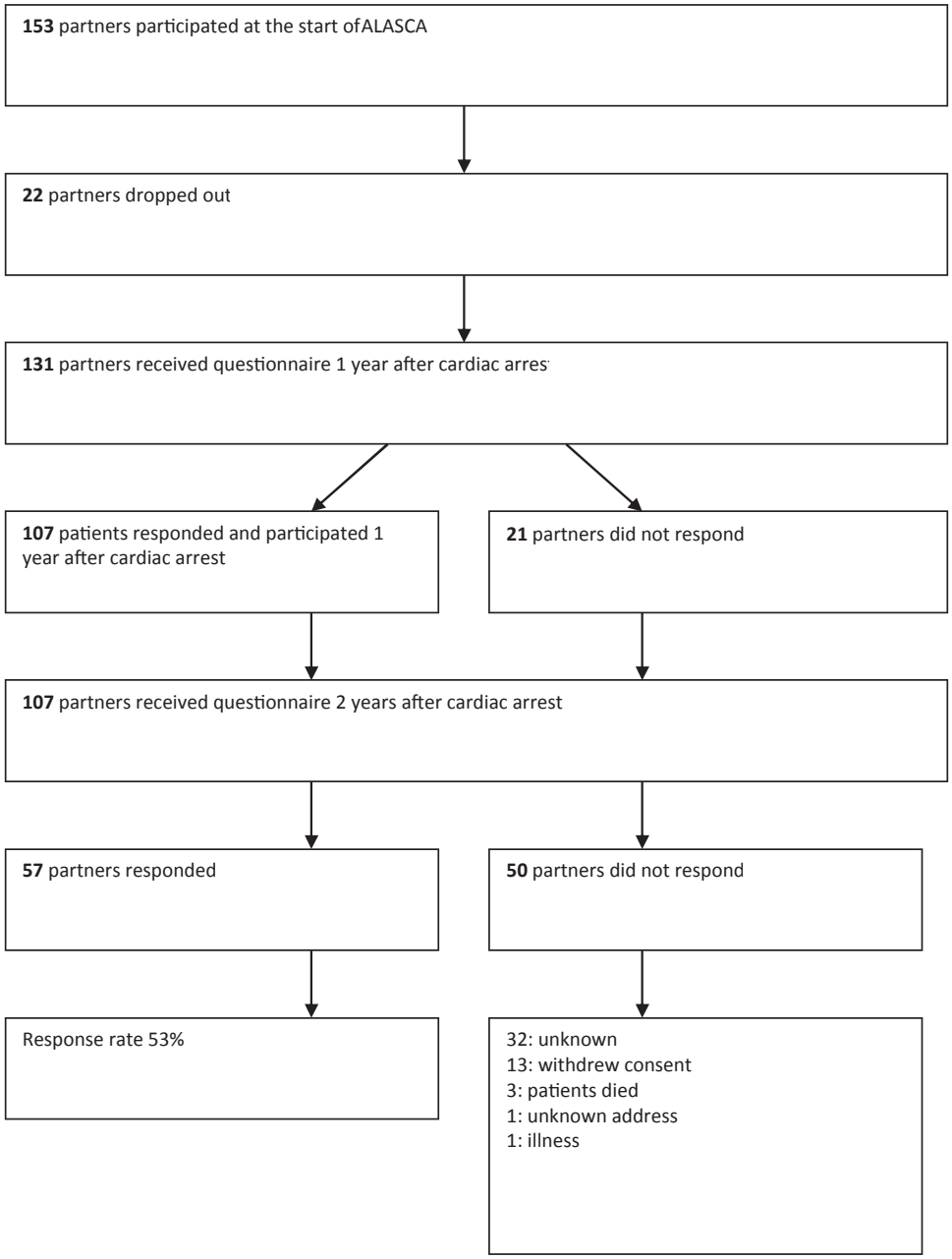

Fig. 1. Flow-chart of patient inclusion.

fatigue in caregivers of renal failure patients and found a mean FSS-score comparable with our study population ($p = .33$) [37].

The level of daily activities was significantly higher in the study population compared to the general population ($p < 0.001$) [28,32]. This finding seems to reflect an active lifestyle of the caregivers, which could be indicated as positive. But this finding could also be due to the fact the patient was no longer capable of performing specific activities that the caregiver had to take over. One year after the cardiac arrest, almost one in five caregivers showed a high level of caregiver burden [13]. After two years, one in seven (14.3%) caregivers experienced strain. This percentage is, however, lower than the 54% found in caregivers of stroke patients and severely brain-injured patients (64%) [11,14]. Stroke survivors are often more ADL-dependent, which can lead to a higher level of physical caregiver strain. However, in contrast to partners of stroke survivors, for partners of patients with a cardiac arrest, it seems that especially emotional instead of physical stress/load still is a concern.

A remarkable finding is that especially caregivers that attended the resuscitation still experienced more stress reactions two years after the event. It could be hypothesized that visualization, feelings of insecurity, guilt and loss of control contribute to this higher level of experienced stress in bystanders. Although results also showed that performing CPR itself did not further increase the level of stress. A study of Robinson et al did, however, not confirm an association between IES-scores and resuscitation attendance [39]. This latter study was, however, conducted in an in-hospital resuscitation setting, in which the caregiver's partner was already in an environment close to medical assistance. It could be that being present during a trauma such as a cardiac arrest suddenly happening to your partner in an insecure situation without medical assistance available is especially traumatizing. It thus seems that caregivers of patients with a cardiac arrest are still influenced by an emotional burden related to the event of the cardiac event itself instead of that they feel a negative impact of caring for their partner on the moment of evaluation.

Table 1
Demographic characteristics caregivers (n = 57).

Gender	
Male	6 (10.5%)
Female	51 (89.5%)
Age	
Mean (S.D.)	56.9 (12.0)
Range	32-77
Education	
Primary School	6 (10.5%)
Secondary School	21 (36.8%)
Intermediate Vocational Education	17 (29.8%)
Higher Vocational Education	9 (15.8%)
University	1 (1.8%)
Unknown	3 (5.3%)
Current working situation	
Full-time	8 (14.0%)
Part-time	21 (36.8%)
Sick leave	1 (1.8%)
On disability pension	3 (5.3%)
Retired	8 (14.0%)
Housewife	10 (17.5%)
Unknown	6 (10.5%)
Resuscitation	
Witnessed CPR	28 (49.1%)
Performed CPR	14 (50%)
Not performed CPR	14 (50%)
Not witnessed CPR	29 (50.9%)

CPR: Cardiopulmonary Resuscitation. CA: Cardiac Arrest.

Table 2
Caregivers of patients with a cardiac arrest two years after the cardiac arrest versus general population (n = 57).

Variable	Study group	N	General population	N	P-value
Qualitiy of life					
Q-5D	0.90 (0.11)	56	0.88 (0.19) [19]	9685	0.29
SF-36					
PCS	80.1 (20.3)	55	76.3 (25.8) [17]	1742	0.17
MCS	80.4 (18.4)	54	77.9 (23.0) [17]	1742	0.31
Emotional functioning					
IES	17.8 (14.8)	56	8.1 (12.3) [22]	138	< 0.001
HADS					
Total score	7.1 (6.5)	57	8.4 (6.3) [20]	199	0.15
Subscale anxiety	4.4. (3.8)	57	5.1 (3.6) [20]	199	0.18
Subscale depression	2.7 (3.1)	57	3.4 (3.3) [20]	199	0.10
Fatigue					
FSS	3.2 (1.6)	57	2.3 (0.7) [25]	20	< 0.001
Instrumental daily activities					
FAI	33.1 (5.8)	56	25.9 (9.4) [28]	216	< 0.001

EQ-5D: EuroQol 5D. SF-36: Short Form 36. PCS: Physical Component Scale. MCS: Mental Component Scale. IES: Impact of Event Scale. HADS: Hospital Anxiety and Depression Scale. FSS: Fatigue Severity Scale. CSI: Caregiver Strain Index. FAI: Frenchay Activities Index.
Information from the general population is provided in the articles as referred to in the table.

This study has some limitations. First, for some questionnaires we had to calculate cut off scores based on previous studies. No other options were available, since there were no cut-off values available from the original articles. Second, the group of participants in which we examine the effect of witnessing and performing CPR is rather small. The two year-questionnaire had a response rate of 57%. Unfortunately, of only 36% of the non-responders a reason for non-response is available. Response can be influenced by attrition bias, although we know that baseline characteristics such as age and gender didn't differ between responders and non-responders. On the other hand, the strength of this study is that it is one of few studies in this area with a longitudinal design and a follow up lasting for two years after the arrest. All caregivers have been assessed on fixed points in time during a follow up period of two year, providing us very valuable information about long-term functioning of caregivers of patients after a cardiac arrest.

Table 3
Differences in scores one year and two years after the cardiac arrest (n = 57).

Variable	1 year post-CA	2 years post-CA	N	P-value
Quality of life				
EQ-5D	0.89 (0.12)	0.90 (0.11)	53	0.69
SF-36				
PCS	83.0 (17.9)	80.1 (20.3)	53	0.05
MCS	83.3 (14.5)	80.4 (18.1)	51	0.23
Euroqol VAS	82.5 (13.6)	79.2 (13.8)	54	0.01
Emotional functioning				
IES	21.1 (15.9)	17.8 (14.8)	53	0.03
HADS				
Subscale Anxiety	4.4 (3.8)	4.4 (3.8)	54	1.00
Subscale Depression	2.4 (3.0)	2.7 (3.1)	54	0.46
Fatigue				
FSS	3.1 (1.4)	3.2 (1.6)	52	0.25
Caregiver strain				
CSI	3.0 (2.7)	3.1 (3.0)	52	0.84

EQ-5D: EuroQol 5D. SF-36: Short Form 36. PCS: Physical Component Scale. MCS: Mental Component Scale. IES: Impact of Event Scale. HADS: Hospital Anxiety and Depression Scale. FSS: Fatigue Severity Scale. CSI: Caregiver Strain Index.

Table 4
Mean scores in CPR bystanders and non-bystanders (n = 57).

Variable	Bystander	N	Non-bystander	N	P-value
Quality of life					
EQ-5D	0.88 (0.10)	27	0.91 (0.11)	29	0.38
SF-36					
PCS	81.4 (19.1)	27	78.9 (21.7)	28	0.95
MCS	80.7 (15.8)	28	80.1 (20.7)	26	0.71
Emotional functioning					
IES	23.6 (14.9)	28	11.9 (12.5)	28	0.002
HADS					
Subscale Anxiety	4.6 (3.6)	28	4.3 (4.0)	29	0.77
Subscale Depression	2.9 (3.1)	28	2.6 (3.1)	29	0.68
Fatigue					
FSS	3.1 (1.5)	28	3.3 (1.7)	29	0.60
Caregiver strain					
CSI	3.5 (3.1)	28	2.6 (3.0)	28	0.29
Instrumental daily activities					
FAI	33.6 (5.9)	27	32.8 (5.7)	29	0.61

CPR: Cardiopulmonary Resuscitation. EQ-5D: EuroQol 5D. SF-36: Short Form 36. PCS: Physical Component Scale. MCS: Mental Component Scale. IES: Impact of Event Scale. HADS: Hospital Anxiety and Depression Scale. FSS: Fatigue Severity Scale. CSI: Caregiver Strain Index. FAI: Frenchay Activities Index.

Implications for clinical practice and future research

This study shows that quality of life of caregivers is quite well two years after a cardiac arrest. But it also shows that a cardiac arrest, and especially attending the event of the cardiac arrest, can cause a high level of trauma related stress in caregivers. More attention for the patient's caregiver is therefore needed. A recent evaluation of an early intervention service for cardiac arrest survivors appeared to be effective in changing mental health of patients, but had no effect in caregivers [40]. In this program caregivers were involved in the program as a partner, but the program was focused on the problems of the patient with a cardiac arrest. It thus seems that caregivers need their own focus on learning to cope with the consequences of the cardiac arrest as a traumatic event. This is especially the case in caregivers that witnessed the cardiac arrest. For stroke caregivers, interventions aimed at psychoeducation and information provision with skills training such as problems solving skills or stress management seems to be favored. Ideally face-to-face contacts are part of the intervention to ensure a tailored

approach [41]. For caregivers of patients with a cardiac arrest, psychoeducation and information provision also seems of additional valuable, however it will probably not be abundant for those that witnessed a cardiac arrest. Further research seems needed to specifically focus on effective support for experienced trauma related stress for those partners that actually witnessed their partner's cardiac arrest.

Conclusion

The results of this study show that quality of life of caregivers of survivors of a cardiac arrest is quite well. But almost one third of caregivers still experience a high level of trauma related stress which seems to be even higher in caregivers that witnessed the resuscitation, than in caregivers that did not witness CPR. Future research will have to focus on screening for stress related to attending a cardiac arrest of a close relative and the effectiveness of support programs for caregivers that attended a cardiac arrest of a close relative.

Conflict of interest statement

All authors hereby declare that they do not have any conflicts of interest

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